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What factors are associated with posttraumatic growth in head and neck cancer carers?

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1. Introduction

Head and neck cancer (HNC) is one of the most common forms of cancer worldwide, with an estimated incidence of 600,000 new cases a year (Mehanna, 2010). HNC occurs mainly in older men and its principal etiological factors are tobacco and alcohol use (Mehanna, 2010). HNC can cause significant problems with eating and appearance and is considered to a particularly debilitating form of cancer (Ross et al., 2010).

A significant amount of HNC is provided in the community, where survivors of HNC are often looked after by family and friends (referred to as carers or caregivers). Caring for someone with cancer, particularly head and neck cancer, can be burdensome and have a significant negative impact on carers' psychological health (Braun et al., 2010; Longacre et al., 2012; McCorry et al. 2009; Schaller et al., 2014). Most research on caring and cancer

therefore understandably focuses on negative psychological states or outcomes. Researchers have recently begun to acknowledge, however, that caring for someone with cancer can also have positive effects (Braun et al., 2007; Tallman et al., 2014). Caregivers, for example, have noted that they often obtain intrinsic rewards from caregiving (Ross et al., 2010). Many of them appear to experience a positive, expanded sense of themselves and their social worlds as a result of helping their relative or friend, as well as an enhanced sense of purpose and a new appreciation for life (Ruf et al., 2009). These positive changes, referred to collectively as posttraumatic growth (PTG), appear to occur not despite the burdens of caring but rather because of them (Morris et al., 2012; Ruf et al., 2009; Sumalla et al., 2009; Tedeschi and Calhoun, 2000; Tallman et al., 2014). PTG means that life becomes fuller and more meaningful as a result of difficult events or situations, such as supporting loved ones with cancer (though not that life becomes less burdensome or that suffering becomes less intense as a result of doing so) (Ruf et al., 2009; Tedeschi and Calhoun, 2004). Traumatic events by themselves are insufficient to trigger PTG, however. PTG also requires that an individual reflect on the experiences that they are going through, and search those experiences for meaning. Thus, PTG is not the result of the trauma but stems from the struggle to make sense of and to cope with that trauma (Ruf et al., 2009).

To date PTG in HNC carers has been much less well-researched than PTG in survivors/patients (this is symptomatic of a wider lack of research on PTG in cancer caregivers as opposed to cancer patients/survivors (e.g. Da Silva et al., 2011; Jarrett et al., 2013; Mystakidou et al., 2015), and the limited-albeit groundbreaking- research that has been conducted has been mainly qualitative in nature (Ruf et al., 2009; Thambyrajah et al., 2010). This reflects a general lack of research into the psychosocial concerns of HNC carers (Longacre et al., 2012; Ross et al., 2010) and into non-distress related quality of life issues in cancer caregivers more generally (Kim et al., 2012). Lack of research into psychological

adjustment in HNC cancer carers in the posttreatment phase of the illness trajectory is especially lacking-most psychosocial research on HNC carers focuses on carers in the acute caregiving stage (the first year after treatment) (Ross et al., 2010). A number of previous conceptual articles and studies of patients, however, have identified factors that could potentially be associated with PTG in HNC carers, particularly in the post-acute period (1 year + after treatment). These include ruminative thinking and reflecting on traumatic events (Zoellner and Maercker, 2006), longer time since diagnosis (Linley and Joseph, 2004; Sumalla et al., 2009 Zoellner and Maercker, 2006), social support (Ho et al., 2011; Schroevers, et al., 2010) and increased income levels (Ho et al., 2011).

2. Purpose

The aim of this study was to investigate and quantify the factors associated with PTG in HNC carers who were more than one year post-treatment. Because PTG is unlikely to be explained by a single factor (Linley and Joseph, 2004), we investigated a number of factors that we hypothesized could influence PTG in these carers. Our specific hypotheses were that:

- Socio-economic factors (social support, cancer related financial stress and strain) would be associated with PTG. We hypothesized that the more social support that individuals had, and the less financial stress and strain that they experienced, the more positively they would interpret and view caring and the more benefits they would extract from the caring experience.
- Cancer related rumination (in the form of worry about cancer returning) would be associated with a higher PTG. We hypothesised that since PTG is connected with increased rumination, carers who thought and reflected more about the cancer-even in a negative context- would experience higher PTG.

- Longer time since diagnosis would be associated with increased PTG, as this would provide a long window of opportunity in which to seek to make sense of events.

3. Methods

The study used a cross-sectional, nonexperimental design.

Sample

This investigation formed part of a larger study that examined the post-treatment experiences of survivors of head and neck cancer. For that study, 583 head and neck cancer survivors completed a questionnaire that examined their unmet needs. We asked all 583 head and neck cancer survivors who had completed the postal survey for permission to contact their caregivers (defined as a family member, friend or another person who had been helping take care of them since their diagnosis, if they had one). Two hundred and eighty five survivors granted us permission. We wrote a letter to all 285 carers providing them with information about the study, and indicated that we would send them a questionnaire a fortnight after they received the initial contact letter. The caregiver inclusion criteria consisted of being (a). designated as the primary caregiver by the survivor and (b). caring for their relative/friend for one or more years. Questionnaires were then sent to all 285 carers, 197 of whom responded (69% response rate). When carers sent back their survey they also had to return a signed consent form. Ethical approval for the carer component of the study was provided by nine Irish university hospital ethics committees. Carers were not paid to take part in the study.

Measures

Demographics

Carers were asked to report the following demographic characteristics: sex; relationship status (married/partner vs. not married/no partners); children (yes/no); employment status; private health insurance (yes/no); medical card (yes/no) (entitling them to free medical care in Ireland-this is generally awarded to people with low incomes). Time since survivors' diagnosis was obtained from the National Cancer Registry of Ireland's patient records database, and was therefore not based on carer self-report.

Post-traumatic growth

The Posttraumatic Growth Inventory (PTGI) is a reliable and validated 21-question instrument that measures growth in relation to five dimensions (relating to others (7 items), new possibilities (5 items), personal strength (4 items), spiritual change (2 items) and appreciation of life (3 items)) (Tedeschi and Calhoun, 1996). For each item respondents were given a statement that described a change that they could have experienced (e.g. 'I have developed new interests'). Respondents were then asked to indicate the degree to which they experienced this change as a result of caring for their relative/friend. The response option for each item was a 5 point likert scales (ranging from '0' ('I did not experience this change as a result of caring for my relative/friend') to '5' (I experienced this change to a very great degree as a result of taking care of my relative/friend')). Scores were summed to generate an overall score in the range 0-105. A higher score implies greater post-traumatic growth. The range of possible scores for each of the five domains depends on the number of questions related to the domain. The Cronbach alpha score for the post-traumatic growth inventory is .9.

Social support

We assessed social support using the OSLO 3 support scale (alpha coefficient .6) (Dalgard, et al., 2006)). The OSLO 3 is a 3 item social support scale that asks the following questions: A) How many people are you close to that you can count on them if you have serious problems (response options: none, 1-2, 3-5, 6+); B) How much concern do people show in what you are doing (response options: 5 point likert scale ranging from a lot of concern to no concern); c) How easy is it for you to get practical help from your neighbours if you need it? (response options: 5 point likert scale ranging from very easy to very difficult). The OSLO 3 generates a total score ranging from 0-8 (classified as poor support), 9-11 (intermediate support) and 12+ (classified as high support). The OSLO 3 has been used in several studies and is considered to have good predictive validity (Boen et al., 2012).

Financial stress and strain

Following the definitions of Francouer (2005) we examined financial stress (which stems from events that are financial stressors on a household) and subjective financial strain (which is an individual's subjective perception of financial strain). Financial stress and strain questions were extracted from Sharp et al., study (2013). Financial stress was assessed with a question on the household's ability to make ends meet in the past month and strain with questions on the impact that caring had on the household's ability to make ends meet and how the carer felt about their household's financial situation since their relative/friend was diagnosed with head and neck cancer. Response options for all three questions were six/seven point likert scales ranging from 'much more difficult'/'very concerned' to 'much less difficult'/'much less concerned' (Sharp *et al.* 2013).

Cancer-related rumination

Cancer-related rumination was assessed with Hodges and Humphris (2009) Worry about Cancer scale. This is a two item instrument that investigates carers' worries about cancer in the past month and about how worried they are that their relative or friend's cancer will return in the future. Questions ask about carers' fear of recurrence in the past month. Answers to the two items are likert scales that are summed to give a total composite score in the range of 0-20. We classified worry about cancer as low if the score <10 , and as high if the score was ≥ 10 .

Analysis

Total scores for each PTGI domain and an overall PTG score were calculated as average scores per question for each of these groups. Descriptive statistics are reported on demographic and other potentially important variables like worry about cancer and social support. Associations between potential explanatory variables and overall PTG score were examined using ANOVA initially. Multivariable linear regression was then used to identify which variables remained associated with overall PTG score when adjusted for other variables.

Variables were considered for inclusion in the final model if the p-value for the F-test in the univariable regression model was at most 0.1 or if the p-value for the likelihood ratio test for that variable in the full model was at most 0.1. We also examined the correlation matrix to check for multicollinearity amongst the independent variables. For our final model, we checked the assumptions for a linear model by plotting residuals versus fitted values of the dependent variable and carried out a heteroskedasticity test to check for constant variance. In addition, we checked the variance inflation factor (VIF) for the variables in our final

model. The variance inflation factor (VIF) for each variable in the final model was no higher than 1.6, providing evidence against multi-collinearity being present in the model. Plotting the residuals against the fitted values, provided no evidence against the assumption of homogeneity of the variance of the residuals. This was confirmed by Cook-Weisberg's test for heteroskedasticity. All analysis was carried out using Stata 12.

Missing data

Although 42 respondents did not answer all 21 questions of the PTGI, 192 of them answered at least 11 questions. For those respondents who answered some, but not all, questions, missing responses were imputed as follows. Average scores were calculated as the mean of non-missing data-items if at least half the items from the corresponding (sub)scale were completed. In order to check the robustness of our results, we conducted a sensitivity analysis in which we fitting the final model to the 155 respondents who answered all 21 questions of the PTGI.

Information on stage at HNC diagnosis of the care recipient was missing for 28 (14%) carers. Since missing stage is generally informative, we created an “unknown” category for this group. For the remaining variables the level of missing data was low (ranging from 1 (<1%) to 11 (5%). In the final regression model, no variable had more than 7 (3%) missing values.

4. Results

Respondents' demographic characteristics are shown in **Table 1**. The majority of respondents were female and were married or had a partner. Most (89%) were Irish. 54% had a medical card which, in Ireland, is means-tested and entitles the bearer to free medical care within the public health system and prescription medications at a nominal charge Just over half (52%)

had private health insurance. 85% of respondents had children. 31% lived in a city, 40% in a town or village and 27% in the countryside.

In the primary analysis (i.e. including imputed data), the mean overall PTG score was 58.2 (95%CI [54.9, 61.7]) (**Table 2**). There was some variability in the average score per question between the domains, with appreciation for life having the highest average score and spiritual change the lowest. The values from the sensitivity analysis (based on the subjects who completed all 21 questions) were almost identical.

In univariate analyses, the mean PTG score did not vary notably across levels of social support (**Table 3**). In contrast, for the three questions related to financial stress and strain, the PTG score differed significantly across categories; the score was higher in those reporting more financial stress or strain. The mean PTG score in those with a low worry about cancer score was less than in those with a high worry about cancer score (**Table 3**). Length of time since diagnosis was also positively associated with PTG score.

In the multivariable analysis (**Table 4**), social support was highly associated with the PTG score: The score increased as level of social support increased; compared to the baseline group (low social support), there was a predicted 8.1-point increase in PTG score in the intermediate support group and a 13.0-point increase in the high support group. Similarly, a high worry about cancer score predicted a 7.2 increase in PTG compared to those with a low worry about cancer score. Other factors that were significantly associated with higher PTG score were finding it more difficult to make ends meet as a result of caring, increased time since diagnosis and the demographic variables; having children, being younger, living in the countryside and being of Irish nationality.

5. Discussion.

This study investigated the factors associated with PTG (post-traumatic-growth) in a sample of 197 carers of survivors of head and neck cancer. We found support for our socio-economic hypothesis that increased social support would be associated with increased PTG; financial problems were also associated with increased PTG, although the result was not in the direction that we anticipated. We also found support for our hypothesis that cancer-related rumination (in the form of worry about cancer) was associated with increased PTG. Both of these findings (worry about cancer and increased financial problems) are – as far as we are aware - original in the HNC posttraumatic growth literature. In addition, we found evidence that a range of demographic factors were associated with increased PTG including having children, being of Irish nationality and living in a rural area. Conversely, we found that older age was associated with a lower PTG score.

It was notable that respondents who found it difficult to make ends meet financially since they began caring had higher PTG scores. This contradicts some previous research in cancer patients (rather than carers) (Ho et al., 2011), which found that cancer patients who have higher income levels have higher PTG scores, possibly because higher income enables them to obtain more informal and formal (health system) support. However head and neck cancer researchers (Ruf et al., 2009) have also noted that PTG is most likely to occur in the context of stressors that threaten to undermine an individual's expectations of their life. Moreover, PTG emerges from suffering and pain; it therefore makes sense that situations that cause suffering (such as financial stress or strain) can lead to PTG. It may well be that income (or financial wellbeing) has a complicated relationship with PTG, with financial concerns- and hardship- being linked to increased PTG; but where PTG is occurring as a result of non-income based stressors, financial situation may provide a moderating effect.

Head neck carer posttraumatic growth

Table 1: Demographic characteristics of carers of survivors of head and neck cancer: numbers, percentages, mean PTGI scores with standard deviations, and p values from ANOVA tests

	N	(%)	PTGI		p-value (ANOVA)
			mean	Standard deviation	
Total	197	100%	58.2	20	
sex					
male	44	22%	56.4	22.7	0.67
female	150	76%	58.1	23.3	
unknown	3	2%			
current marital status					
married/partner	172	87%	58.9	23.4	0.33
not married	25	12%	54	22.8	
unknown	-				
nationality					
Irish	176	89%	58.4	23.3	0.36
other	14	7%	52.6	19.7	
unknown	7	4%			
medical card (document that entitles bearer to free medical care in Ireland)					
yes	106	54%	58.2	23.9	0.79
no	87	44%	57.2	22.6	
unknown	4	2%			
private medical insurance					
yes	102	52%	54.4	23.5	0.09
no	84	43%	60.2	22.7	
unknown	11	5%			
have children					
yes	168	85%	58.9	22.8	0.07
no	24	12%	50.1	23.7	
unknown	5	3%			
education					
secondary school	131	66%	59.4	23.5	0.29
college/university	61	31%	55.6	22	
unknown	5	3%			
area of residence					
city	61	31%	52.3	25.5	0.06
town/village	78	40%	58.8	23.6	
countryside	53	27%	62.6	19.2	
unknown	5	2%			
ever been diagnosed by a doctor with a serious medical condition					
at least one	102	46%	58.0	25.6	0.88
none	91	52%	58.5	21.5	
unknown	4	2%			
employment status					
paid employment	64	32%	60.3	24.1	0.57
looking after family/home	52	26%	58.9	24.9	
retired/unemployed/disability	80	41%	56.2	21.9	
unknown	1	(<1%)			
stage of relative/friend's cancer					
I	62	32%	53.0	27.6	0.26
II	28	14%	56.7	20.9	
III	22	11%	60.5	24.1	
IV	57	29%	61.9	19.8	
unknown	28	14%	61.7	20.7	

Table 2: PTGI scores, overall and for each of the five domains: primary analysis (imputed data) and sensitivity analysis (complete case)

	no of questions	Min no. of questions required to impute PTGI	complete case for participants who answered all 21 PTGI questions (sensitivity analysis)			imputed data (primary analysis)			
			total score [95% CI]	average score per question	number of respondents used to calculate this score	Total score [95% CI]	average score per question	number of respondents used to calculate this score	
overall	21	11	58.2 [54.5, 61.9]	2.8	155	58.2 [54.9, 61.7]	2.8	192	
relate to others	7	4	20.3 [19.0, 21.6]	2.9	175	20.4 [19.1, 21.6]	2.9	191	
new possibilities	5	3	10.8 [9.8, 11.7]	2.2	176	10.9 [9.8, 11.7]	2.2	191	
personal strength	4	3	12.1 [11.4, 12.8]	3.0	182	12.2 [11.5, 12.9]	3.0	191	
spiritual change	2	2	4.3 [3.7, 4.8]	2.1	183	4.3 [3.7, 4.8]	2.1	183	
appreciation of life	3	2	10.8 [10.2, 11.3]	3.6	187	10.8 [10.3, 11.3]	3.6	193	

Table 3. Socio-economic factors, cancer-related rumination and time since diagnosis: numbers, percentages, mean PTGI scores with standard deviations, and p values from ANOVA tests

			PTGI		
	N	(%)	mean	Standard deviation	p-value (ANOVA)
Time since diagnosis					
1-5 years	91	46%	55.4	23.7	0.25
5-10 years	70	35%	61.7	22.3	
10+ years	29	15%	57.5	25	
unknown	7	4%			
Cancer-related rumination					
worry about cancer					
low	91	47%	53.5	25.5	0.01
high	100	52%	62.1	20.8	
unknown	3	2%			
Socio-economic factors					
amount of social support available to carer in his/her social network					
low	52	26%	53.3	23.7	0.10
intermediate	78	40%	58.7	20.9	
high	62	31%	62.7	24.7	
unknown	5	3%			
how difficult was it to make financial ends meet in the past month?					
difficult	100	51%	62.0	22.5	0.02
easy	96	49%	54.3	23.8	
unknown	1	(<1%)			
impact of caring on ability to make ends meet					
makes it more difficult	94	48%	63.7	21.7	<0.01
no impact/makes it less difficult	98	45%	53.3	24	
unknown	5	2%			
level of concern about household finances since relative/friend's diagnosis					
more concerned	114	58%	62.6	21.3	<0.01
same/less concerned	80	41%	51.6	24.8	
unknown	3	2%			

Table 4: Significant predictors of PTGI from multivariable linear regression: coefficients, standard errors, 95% confidence intervals and p values

	estimate	(SE)	[95% Conf.	Interval]	p-value likelihood ratio test
worry about cancer					
low	ref				
high	7.2	(3.2)	0.8	13.6	0.0226
amount of social support available to carer in his/her social network					
low	ref				
intermediate	8.1	(4.1)	0.0	16.1	0.0067
high	13.0	(4.2)	4.7	21.3	
nationality					
other	ref				
Irish	17.1	(6.5)	4.2	30.0	0.0070
have children					
no	ref				
yes	10.1	(5.0)	0.2	20.0	0.0370
effect of caring on ability to make ends meet					
no impact/makes it less	ref				
difficult					
makes it more difficult	10.4	(3.4)	3.7	17.0	0.0016
time since diagnosis					
1- 5years	ref				
5-9 years	7.4	(3.5)	0.5	14.3	0.0478
10+ years	9.0	(5.2)	-1.2	19.2	
area of residence					
city	ref				
town/village	8.4	(3.9)	0.6	16.1	0.0015
open countryside	15.1	(4.3)	6.6	23.5	
age at the time of survey	-0.4	(0.1)	-0.6	-0.1	0.0076

$R^2 = 26.8\%$, adjusted $R^2 = 21.5\%$, $n = 163$

It may also be that carers take on the responsibility of financial management after their relative/friend has been diagnosed and protect patients from the reality of financial difficulties (perhaps as a form of protective buffering). This could mean that carers are exposed to increased financial stress and strain (to a greater degree than patients are), allowing PTG to stem from that stress among carers.

The study found that social support, as measured by the Oslo support scale, was strongly linked to PTG. The relationship between social support and PTG has been previously identified (Ruf et al., 2009; Schroevers et al., 2010; Weiss, 2004). Social support may enable individuals to cognitively process trauma, to make sense and meaning out of it; other people can offer their perspectives and beliefs about the difficulties that the individual

is experiencing, thereby allowing the individual to positively reframe what is happening to them (Schroevers et al., 2010; Tedeschi and Calhoun, 2004; Weiss, 2004). One reason why rural residence could be associated with PTG is that older people from those areas may be more likely to be part of tightly integrated and supportive local communities compared with their counterparts living in urban areas. However it may also be that rural residence could in some situations be linked to isolation and lack of support; more research is needed here. Additionally it seems plausible that individuals of Irish nationality may have easier access to wider and more stable social support networks than people of non-Irish nationality.

Worry about cancer (partly stemming from fear of cancer recurrence (FOR)) emerged in this study as a statistically significant predictor of PTG. Although fear of cancer recurrence has often been thought of as being a primary concern for patients, it is common amongst carers as well (Hodges and Humphris, 2009; Longacre et al., 2012). To a certain extent the relationship between worry about cancer and PTG that was detected in this study is surprising as FOR has been previously associated with psychological morbidity and reduced quality of life in cancer patients and their partners (Handsichel et al., 2012; Hodges and Humphris, 2009). However like financial concerns, the suffering associated with fear of recurrence may provide fertile ground from which PTG can emerge. Worry about cancer, and especially fear of recurrence, may additionally be related to PTG because these anxieties are associated with an individual thinking about their experiences and where they think that their life (and their relative/friend's life) is going in the future. Previous research suggests that the more than an individual 'constructively ruminates' and contemplates the changes brought about in their lives by traumatic situations, the more likely they are to finding meaning in the trauma and from their struggle to master it (Weiss, 2004). Individuals who strongly fear that their relative or friend's cancer will recur may therefore be engaged in repeated cognitive processing about the cancer, its impact and the meaning that it has for them, which may increase the likelihood

that they will experience some form of PTG (Linley et al., 2004; Tedeshi and Calhoun, 2004).

Time was an important factor in explaining carers' PTG, with length of time since diagnosis positively associated with PTG scores (though this result was only just statistically significant at the 5% level in multivariable analysis)). It has previously been suggested that time since trauma (conceptualized here as length of time since diagnosis) is connected with PTG (Linley and Joseph, 2004; Manne et al., 2004) though other studies have found that length of time since the critical event does not influence PTG (Tedeshi and Calhoun, 2004). It is thought that as time passes individuals might be able to more easily make sense of the traumatic events; and time passing also allows more supportive events and processes to come into play and enable the individual to more positively reframe what has happened to them (Linley and Joseph, 2004). The finding that younger age can facilitate PTG has been noted previously (Linley and Joseph, 2004; Manne et al., 2004), though not in relation to HNC carers. The reasons why younger people experience more PTG are unclear. It is possible that that younger people might feel more positively about the future and its potential possibilities than older people, or that older people may hold more fatalistic (possibly realistic) beliefs about cancer and its progress thereby being less likely to see benefits in it.

The study's principal limitation is its cross-sectional design which means that we were unable to monitor changes in PTG over time. The factors that trigger PTG in the immediate aftermath of cancer diagnosis or treatment may be different from those that facilitate PTG over the longer post-treatment period. However the study also has a number of strengths, not least of which is that it is one of the largest international studies to investigate and quantify posttraumatic growth in head and neck cancer carers. Most previous studies in this area have been smaller, qualitative projects (Thambyrajah et al., 2010).

6. Implications for practice

The findings of this study have a number of clinical implications for nurses and other health professionals who work with this group. One is the importance of recognizing that trauma may also be a potential precursor to growth in some HNC caregivers (Zoeliner and Maercker, 2006). This understanding broadens the clinical perspective and should encourage nurses to pay more attention to the full-spectrum of carer experience, and not simply focus on illness related deficits (Zoeliner and Maercker, 2006). Clinicians cannot undo the trauma that cancer caregivers experience, though they might be able to assist them to live more meaningfully. How would they do this? The findings of this study suggest that posttraumatic growth is strongly linked in head and neck cancer caregivers to social support. Carers with few extant social resources may therefore benefit from formal clinical efforts to provide them with social support, for example in the form of specialist peer support groups (Schroevers et al., 2010). Providing carers with opportunities to reflect and talk about their experiences on a one to one basis may also facilitate constructive rumination in at least some carers, and potentially lead them to obtain some psychological benefit from what may otherwise be a very distressing experience. More research is needed to determine if there are certain points in the caregiving trajectory where such support could best foster posttraumatic growth (Larsson et al., 2007). Given the historical lack of counselling and psychological support for head and neck patients (Moore et al., 2014), let alone carers, dedicated staff time needs to be set aside to enable nurses and other professionals to facilitate such support groups and networks.

Conflict of interest

None declared

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